Understanding and Managing Parkinson's Disease

A Program for Healthcare Professionals

Presented by

Parkinson's Disease Research, Education & Clinical Center

Veterans Health Administration
Department of Veterans Affairs

Employee Education System

Virginia, Western Reserve, Mountain State and Pennsylvania
Consortia of Geriatric Education Centers

VIRGINIA GERIATRIC EDUCATION CENTER

WRGEC Western Reserve Geriatric Education Center

MSGEC

GEC/PA

Geriatric Education Center of Pennsylvania

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Program Overview

In 2001, the Veterans Health Administration (VHA), one of three major branches in the Department of Veterans Affairs, created six Parkinson's Disease Research, Education and Clinical Centers (PADRECC) in an effort to improve care for veterans with Parkinson's disease and to pursue treatments and a cure for this condition. The centers are located in Philadelphia, Richmond, Houston, Portland/Seattle, San Francisco and West Los Angeles.

Veterans have access to innovative strategies and treatment interventions to improve functional ability and life satisfaction as well as opportunities to participate in cutting edge research intended to lead to more effective treatments. Other PADRECC services include but are not limited to interdisciplinary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, telemedicine, caregiver resources, educational materials, community education programs, patient and family programs, support groups and programs to educate healthcare professionals.

Parkinson's disease is a complex degenerative neurological condition that affects patients differently and management strategies must address the particular needs of each patient. As the disease progresses, symptoms can become quite challenging to treat and manage. A firm understanding of the disease process and its management is essential in the provision of appropriate and quality care.

This training program offers specialized training of physicians, nurses and allied staff in the treatment and management of people with Parkinson's disease. This educational initiative is aimed at increasing the level of understanding of Parkinson's disease, the array of treatment and management strategies, the available resources and the impact that this disorder can have on patients and families in an effort to improve the quality of patient care.

This initiative targets health professionals within two organizations, the VA System and Geriatric Education Centers (GECs). The GEC program is supported by the Health Resources and Services Administration, Bureau of Health Professions. It offers training for health professionals in geriatrics; curricula relating to the treatment of the health problems of elderly individuals; training and retraining of faculty to provide instruction in geriatrics; continuing education of health professionals who provide geriatric care; and clinical training in geriatrics in nursing homes, chronic and acute disease hospitals, ambulatory care centers, and senior centers. This project is the second joint venture of the Mountain State, Pennsylvania,

Virginia, and Western Reserve GECs. The Virginia GEC has successfully presented over 27 national videoconferences and took the lead to form the consortia that helped to support this program.

This national teleconference was originally broadcasted in November 2003 and then again in December 2003 and involved six-30 minute educational modules. Consumers and health professionals associated with both organizations face numerous challenges associated with Parkinson's disease and other disorders. The program builds on the educational needs that are relevant to caregivers in organizations served by the VA and the network of 46 GECs in caring for patients with a complex chronic disease. It not only provides an innovative educational opportunity, but it also fosters collaboration among multiple governmental programs and the larger health care community. Through these collaborative efforts of the PADRECCs, GECs and EES, improved care to people with Parkinson's disease can be provided within the VA health system and the larger healthcare and consumer communities.

Target Audience

The program is intended for health care providers within the Veterans Healthcare Administration (VHA) and private sector who are involved in diagnosing and treating people with Parkinson's disease and those who work with older adults. This includes but is not limited to physicians, nurses, and therapists.

Outcome Objectives

At the conclusion of the broadcast the learner will:

- Describe the VA's unique development of a national Parkinson's disease (PD) program through the formation of PADRECCs.
- Recognize the mission of the Geriatric Education Centers (GECs) and the benefits of working collaboratively with them.
- Recognize the significance of this national educational initiative for providing an innovative educational opportunity for healthcare providers and for fostering collaboration among multiple governmental programs.
- Analyze the pathophysiology of Parkinson's disease.
- Identify the cardinal and secondary signs and symptoms of Parkinson's disease.
- Identify other forms of Parkinsonism and how to formulate a differential diagnoses.
- Analyze the importance of multidisciplinary care and the need for individualized treatment as the disease progresses.
- Identify the major classes of medications used in the treatment of Parkinson's disease, their mechanism of action, and side effects.
- Discuss treatment guidelines for prescribing and administering anti-parkinsonian medications and the need for individualized treatment regimens.
- Identify the major problems that people with Parkinson's disease may face when hospitalized and the assessment and treatment strategies to prevent/reduce these major problems.
- Identify medications that should be avoided in people with Parkinson's disease.
- Identify resources that are helpful in fostering compliance such as patient diaries and drug lists.
- Recognize how patients, families and healthcare providers can better prepare for future hospitalizations and/or visits to the doctor.
- Recognize the effects of Parkinson's disease on gait and balance and the need for fall prevention strategies.
- Recognize the importance of exercise and physical therapy in managing Parkinson's disease.
- Recognize the role of occupational therapy in the management of PD.
- Identify common speech and swallowing problems in people with PD and identify proper assessment and management strategies.
- Recognize dietary considerations of people with Parkinson's disease.
- Identify helpful strategies to maintain or improve nutritional health.
- Identify the common types of cognitive impairment in PD.
- Identify common psychiatric and other non-motor complications in PD.
- Recognize screening instruments and assessment techniques.
- Recognize interventions to reduce, improve, and better manage neuropsychiatric complications.
- Recognize the psychosocial issues facing patients and their families and the services, support programs and educational materials that are available.
- Recognize the history of surgery in Parkinson's disease and what approaches are used today.
- Analyze the indications and contraindications for deep brain surgery.
- List the characteristics of patients who are most likely to benefit from surgery.
- Describe current research being conducted involving surgical therapies.

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Faculty Disclosure(s) The Employee Education System (EES) must insure balance, independence, objectivity, and scientific rigor to all EES sponsored educational activities. The intent of this disclosure is not to prevent faculty with a significant financial or other relationship from presenting materials, but rather to provide the participant with information on which they can make their own judgments. It remains for the participant to determine whether the faculty interests or relationships influence the materials presented with regard to exposition or conclusion. When an unapproved use of a FDA approved drug or medical device, or an investigational product not yet FDA approved for any purpose is mentioned, EES requires disclosure to the participants.

The following was reported by program faculty or planning committee members:
Dr. Daniel Weintraub reported receiving grant support from Forest Pharmaceuticals Inc. to conduct an antidepressant study in Parkinson's disease using *escitalopram*.

Dr. William Marks reported receiving grants from Medtronic Neurological and serving on its Speakers Bureau.

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Accreditation/Approval

The original broadcast was approved by the following:

Accreditation Council on Continuing Medical Education (ACCME) The VA Employee Education System is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians. This activity was certified to provide continuing education credit to practitioners seeking category 1 AMA PRA credit when viewed the live, scheduled rebroadcast or a recording.

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Continuing Education Credit

Continuing education credit was granted by the following:

Accreditation Council for Continuing Medical Education (ACCME) The VA Employee Education System designated this educational activity for a maximum of 3 hours in category 1 credit towards the American Medical Association Physician's Recognition Award. Continuing education credit will not be offered by the VA employee Education System for the viewing of the broadcast, the re-broadcast or a tape of the broadcast after February 1, 2004.

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To Order the Program

Understanding and Managing Parkinson's Disease: A Program for Healthcare Professionals is available for purchase through the Virginia Geriatric Education Center (VGEC). The 2-video series and handout can be purchased for $30.00. An order form is available through the VGEC website at www.sahp.vcu.edu/gerontology/ or the national PADRECC website at www.va.gov/PADRECC. An electronic copy of the handout and Power Point slides can also be downloaded at no charge from these two sites. If there are problems or questions, please contact: Ms. Kathleen Watson, Senior Project Coordinator, Virginia Geriatric Education Center, 804.828.9060 or e-mail at kdwatson@vcu.edu.

Part I

Module 1

Introduction & Overview of Parkinson's Disease

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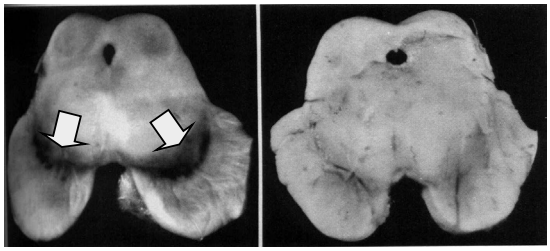
An electronic copy of the handout and Power Point slides are available at no charge. Please visit the Virginia Geriatric Education Center website at www.sahp.vcu.edu/gerontology/ or the national PADRECC website at www.va.gov/PADRECC to download this information.

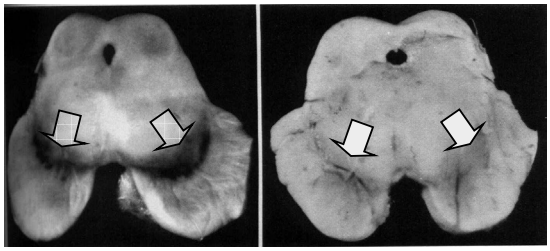
Parkinsonism

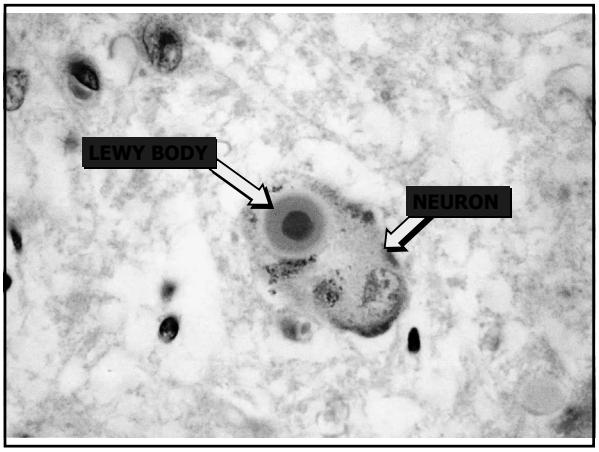
A syndrome characterized by rest tremor, rigidity, and slowness of movement.

Parkinson's Disease

Parkinsonism with no known cause, generally responsive to levodopa, and pathologically characterized by loss of dopamine neurons in the substantia nigra and presence of Lewy bodies in some remaining dopaminergic neurons.







Parkinson's Disease

Prevalence

- **1-2/1000 people**
- **1-2/100 people older than 60**

Life span: 15 to 20 years

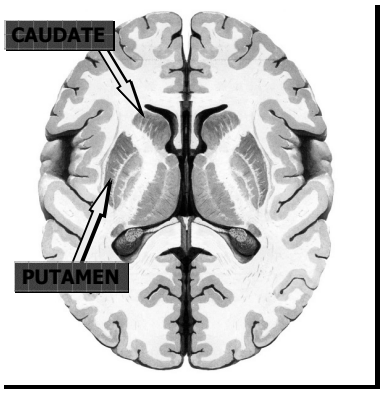
Progressive and multifaceted

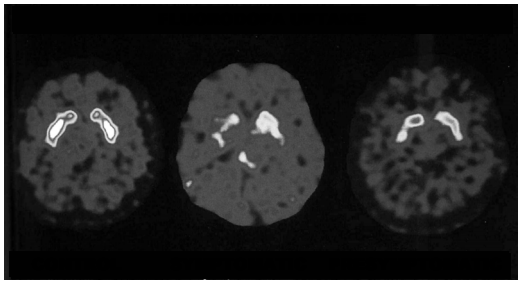
Tremor

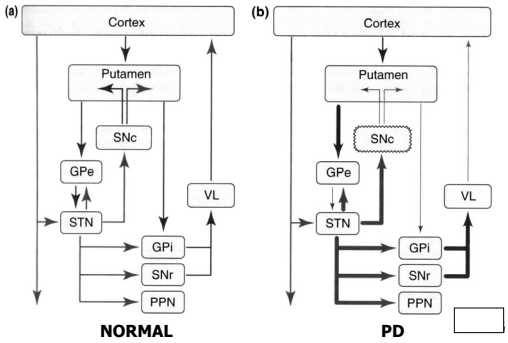
	Rest	
Posture:	Limb at rest, hanging by side	
Movement:	Reduces tremor	
Symmetry:	No	
Affects:	Arms, legs, jaw, tongue	
Differential:	Parkinsonism	

Tremor

	Rest	Postural
Posture:	Limb at rest, hanging by side	Limb in a sustained posture
Movement:	Reduces tremor	Tremor persists
Symmetry:	No	Yes
Affects:	Arms, legs, jaw, tongue	Arms, head (neck)
Differential:	Parkinsonism	Essential tremor, drugs, toxins, other neurological diseases







Parkinsonism: Etiology

- Toxins
- Infections
- Trauma
- Hydrocephalus
- Vascular

Parkinsonism: Drug-Induced

- Antipsychotics
- Antiemetics
- Antihypertensives

Parkinson's Disease Diagnosis: Red Flags

- Wide-based gait
- Dementia at onset of PD
- Falls at onset of PD
- Prominent autonomic signs at onset
- Other neurological signs

Geriatric Education Centers

Part I

Module 2

Medical Management of Parkinson's Disease

Faculty:

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John Nutt, M.D.

An electronic copy of the handout and Power Point slides are available at no charge. Please visit the Virginia Geriatric Education Center website at www.sahp.vcu.edu/gerontology/ or the national PADRECC website at www.va.gov/PADRECC to download this information.

Medical Management of Parkinson's Disease

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Parkinson's Disease (PD) is a chronic progressive disorder. Current treatment modalities are geared towards symptomatic relief, aimed at replenishing dopamine deficit. Most of the therapeutic efforts are aimed at reducing the cardinal symptoms of the disease and improving functional capacity. Choice of therapy depends on severity of disease, overall disability, patient age, concurrent medical problems tolerance of adverse effects and presence of treatment complications.

Goals of Therapy

1. Reverse motor symptoms of disease
2. Limit or stop the progression of disease
3. Limit or treat complications of disease
4. Treat psychiatric, autonomic and systemic complications of disease

Medications used in the treatment of PD can be classified as follows:

1. Dopaminergic agents
2. Anticholinergics and NMDA antagonists
3. Non-dopaminergic agents for non-motor symptoms

Dopaminergic Agents

Dopamine precursor: levodopa
Decarboxylase inhibitor: carbidopa
Catechol-O-methyltransferase inhibitors: entacapone, tolcapone
Dopamine agonists: bromocriptine, pergolide, pramipexole, ropinirole
MAO type B inhibitor: selegiline

►**Carbidopa/Levodopa** (Sinemet®, Sinemet CR ®), Levodopa (Dopar®), Carbidopa (Lodosyn®) (See Figure 1)

Dopamine does not cross the blood-brain barrier, however levodopa does and is converted to dopamine in the CNS by dopa decarboxylase.

Carbidopa is a noncompetitive inhibitor of dopa decarboxylase and prevents the peripheral conversion of levodopa to dopamine, thereby preventing some of the unwanted side effects such as nausea and orthostasis. Doses needed to inhibit enzyme activity – 75 to 100mg.

Levodopa: Pharmacokinetics: Peak action: 30 to 90 minutes; Peak brain levels reached 1 hour later; Half life: 50 minutes when given alone but 1.5 hours when given with carbidopa. Levodopa is absorbed in the small intestine so drug that effect gastric emptying time can alter absorption; also amino acids form dietary protein compete for levodopa absorption and transport into the CNS.

Sinemet – regular release is available in 10:1 and 4:1 ratio of (Carbidopa/Levodopa) and strengths available are as follows: 10/100, 25/250, 25/100.

Sinemet CR -controlled release formulation is available in the following strengths 50/200, 25/100. Sinemet CR has a slower onset of action, but see fewer fluctuations in plasma concentrations of levodopa.

Bioavailability of combination product Sinemet:
Oral, standard formulation: 80 to 98%
Oral, controlled release: 63% (fasting) and 71% (light breakfast)

Side effects: Nausea, anorexia, vomiting, confusion, drowsiness, behavioral changes, vivid dreams, nightmares, frank hallucinations, postural hypotension, cardiac arrhythmias and dyskinesias.

►**Catechol-O-methyl transferase (COMT) inhibitors**: COMT is one of the major enzymes in dopamine catabolism. (See Figure 1)

●**Tolcapone** (Tasmar®)**:** Selective reversible COMT inhibitor, peripheral and centrally. When given with levodopa and carbidopa it prevents breakdown of levodopa to 3OMD in the gut thereby increasing levodopa concentration in blood stream and increases the half-life and AUC of levodopa by up to 100%.

Adverse effects: 3 reports of death due to ***liver toxicity*** (risk is 1in>20,000). It is recommended that patients have liver enzymes monitored every 2 weeks for the 1st year of therapy then every month for the next 6 months followed by every 6 months thereafter; diarrhea, nausea, postural hypotension, dizziness, urine discoloration and prolongation and increase of levodopa-induced side effects.

Dose: 100 to 200 mg 3 times daily

●**Entacapone** (Comtan®): Highly selective, reversible COMT inhibitor, peripheral only. It inhibits COMT activity in the gut, erythrocytes and liver.

Adverse effects: Diarrhea, nausea, dizziness, urine discoloration (orange), prolongation & increase of levodopa induced side effects, including dyskinesias.

Dose: Due to its short half-life, entacapone should be given with every levodopa dose. Dose is range from 100 to 200 mg given 4 to 8 times daily. Daily maximum recommended dose is 1600 mg/day.

►**Dopamine Agonists:** Dopamine agonists can be used as initial therapy or added to levodopa therapy. They are all beneficial for tremor, rigidity and bradykinesia but not for postural instability. They directly stimulate striatal dopamine receptors. Dopamine agonists are considered the agents of choice for managing patients with mild, uncomplicated, symptomatic PD as they are less likely to induce dyskinesias and motor fluctuations.

All dopamine agonists can induce confusion and hallucinations in elderly patients. Additionally, all dopamine agonists have a propensity to cause ankle and leg edema along with redness with long term treatment. The edema and redness subsides once the dopamine agonist has been discontinued and substituted with levodopa therapy. Re-challenge with another dopamine agonist does not prevent recurrence of edema and redness. Additionally, each of the dopamine agonists can cause orthostatic hypotension upon initiation. Therefore, it is best to start therapy with a low bedtime dose.

●**Ergot-derived dopamine agonists**

An uncommon side effect associated with ergots is a red inflamed skin (St Anthony's fire) that is reversible once the medication is stopped. Another rare side effect seen with long-term use of ergots is soft tissue fibrosis affecting the retroperitoneum, lungs and cardiac valves.

○ **Bromocriptine** (Parlodel®) stimulates D_2 receptors and mildly blocks D_1 receptors.
Adverse effects: Nausea, constipation, orthostatic hypotension, postural hypotension, dyskinesias, confusion, agitation, hallucinations, drowsiness, lightheadedness, nervousness, depression, anorexia, anxiety, nasal congestion, nightmares, myoclonus
Dose: Start with 1.25 mg twice daily and titrate to 15 to 20mg /day given in 2 to 3 divided doses.

○**Pergolide** (Permax®): activates both D_2 and D_1 receptors. It is more potent than bromocriptine.
Adverse effects: Similar to bromocriptine
Dose: 1 to 4 mg /day given as 3 divided doses. Initiate therapy with 0.05mg once daily for 2 to 3 days and increase by 0.1 to 0.15 /day every 3 days as tolerated to effective dose.

●**Non ergot derived dopamine agonists**

○**Pramipexole** (Mirapex®) is a D_2 receptor agonist and is better tolerated than older dopamine agonists. It is excreted really unchanged; doses need to be adjusted in patients with renal impairment.

Adverse effects: Somnolence, nausea, dizziness, hallucinations, constipation, and orthostatic hypotension. When given as an adjunct with levodopa can cause dyskinesias and hallucinations.
Dose: Initiate therapy with 0.125 mg 3 times daily for 1 week; titrate to 1.5 to 4.5 mg by increasing dose weekly.

○**Ropinirole** (Requip ®) is a D_2 receptor agonist and is better tolerated than older dopamine agonists. It is metabolized in the liver by CYP1A2

Adverse effects: nausea, dizziness and somnolence, orthostatic hypotension, syncope, dyskinesia, asthenia, fatigue, hallucinations and confusion.
Dose: Initiate therapy at 0.25mg/day; titrate weekly to 6 to 24mg in 2 divided doses.

►**Selegiline** (Eldepryl®) is a synthetic, selective, irreversible inhibitor of MAO B and is used in the treatment of mild PD and in advance PD for treatment of wearing-off phenomenon. It is metabolized to methamphetamine and amphetamine and this contributes to side effects (insomnia).

Adverse effects: Exacerbation of levodopa-induced side effects when given with levodopa: Orthostatic hypotension, nausea, constipation, dyskinesias, confusion, hallucinations, vivid dreams, insomnia, dizziness, headache, benign cardiac arrhythmias, dry mouth and confusion in elderly. Additionally, there have been case reports of Serotonin syndrome when selegiline was combined with meperidine, imipramine, lithium, clomipramine, sibutramine and high dose dextromethorphan.

Dose: 5 mg twice daily and with 2nd dose to be taken no later than 2:00 p.m.

Anticholinergics and NMDA antagonists

►**Anticholinergics**

In PD selective degeneration of nigra-striatal neurons permits putative overactivity of cholinergic output. Anticholinergic therapy was the mainstay of PD prior to the advent of dopaminergic therapy. Anticholinergics such as trihexyphenidyl and benztropine are effective but inferior to dopaminergic agents in treating PD. They are used as adjunctive therapy and occasionally as 1st line in the treatment of young patients with tremor predominant disease and minimal bradykinesia and rigidity. They are also primarily used for drug induced Parkinsonism.

Adverse effects: reversible dose dependent muscarinic side effects such as constipation, urinary retention, dry mouth, blurred vision, sedation, tachycardia, memory impairment, hallucination and confusion (elderly patient). These agents are not recommended in the elderly patients due to their troublesome side effects. Additionally, if used as adjunctive therapy with levodopa, delayed gastric emptying may inhibit levodopa absorption.

►**Amantadine** (Symmetrel®) is a mild direct dopaminergic agent. Its mechanism appears to be release of dopamine form nerve terminals and possible inhibition of re-uptake of dopamine. Additionally, it is appears to have some anticholinergic properties as well as glutamate receptor blocking activity. It is used as monotherapy in early PD; adjuvant agent in patients taking dopamine agonists and levodopa; and levodopa-induced dyskinesias in advanced PD. Some patients may experience tachyphylaxis to monotherapy after 4 to 8 weeks.

Adverse effects: livedo reticularis, ankle edema, orthostatic hypotension, dry skin or eczema and central effects such as confusion, nightmares, hallucinations, insomnia and mild anticholinergic effects.

Dose: Initiate therapy at 100mg/day and increase to 100mg 3 times daily as needed.

Agents for treatment of Non-motor symptoms
Patients with PD experience a variety of non-motor symptoms such as orthostatic hypotension, urinary incontinence, constipation, sexual dysfunction, dysphagia, depression, dementia, drug-induced psychosis, restless leg syndrome, pain, fatigue and sleep difficulties.

Table 1: Management of autonomic symptoms in PD

Orthostatic hypotension	Fludrocortisone, midodrine, encourage fluid and salt intake, review medications
Urinary incontinence	Oxybutynin, tolteridine, nocturnal desmopressin intranasal spray, bladder training and voiding schedules
Constipation	Increase fiber content of diet, stool softeners, laxatives, avoid anticholinergic medications, enemas
Sexual dysfunction	Erectile agents, review medications
Dysphagia	Optimize treatment of PD, soft diet, feeding gastrostomy,

****** VA Formulary Reminder***
Some drugs or classes of drugs discussed may not be listed on National VA formulary or have approved VHA treatment guidelines. Some drugs may be available through "VISN" formularies or non-formulary drug request process.

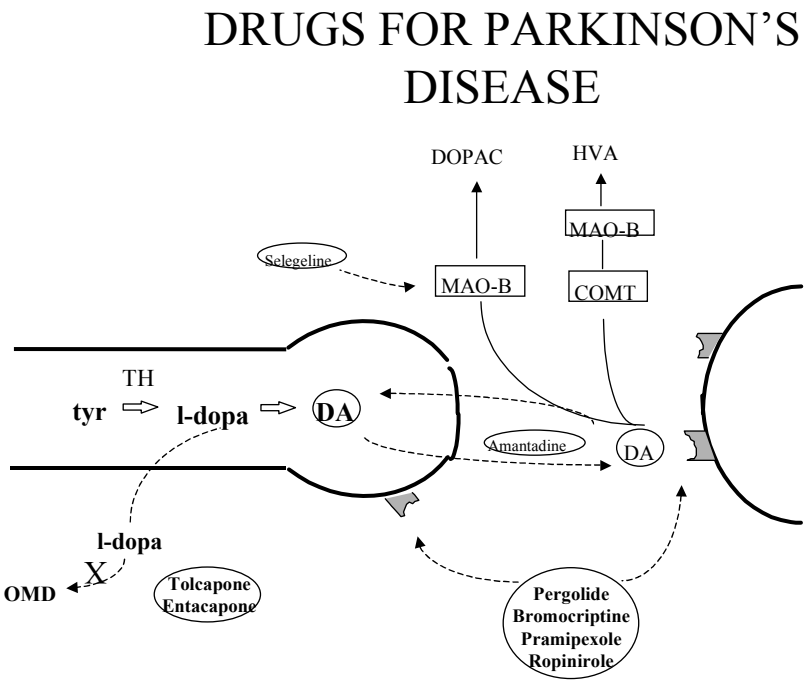

Figure 1

Therapeutic Targets

- Motor Symptoms
- Depression
- Cognitive Impairments
- Psychosis
- Sleep Disturbances
- Autonomic Dysfunction

Dopaminergic Drugs

- Dopamine precursor: levodopa
- Decarboxylase inhibitor: carbidopa
- Catechol-O-methyl transferase inhibitors: entacapone, tolcapone

Dopaminergic Drugs

- Dopamine agonists: bromocriptine, pergolide, pramiprexole, ropinorole
- MAO type B inhibitor: selegiline

Non-dopaminergic Drugs

- Anticholinergics
  - Trihexyphenidyl
  - Benztropine
- Antiglutamatergic
  - Amantadine

Dopamine Agonists as Initial Therapy

- Directly stimulates striatal dopamine receptors
- Less effective than levodopa
- Low incidence of motor fluctuation and dyskinesia
- Higher incidence of hallucinations

Other Initial Therapies

- Levodopa
- Anticholinergics
- Amantadine

Management of Early Adverse Effects

- Gastrointestinal symptoms
  - "Start low go slow"
  - Administer with meals
  - Supplemental Carbidopa
  - Domperidone
- Orthostatic hypotension
  - "Start low go slow"
  - Evening dosing

Management of Other Adverse Effects

- Excessive daytime sleepiness
- Hallucinations and Psychosis
- Edema
- Fibrosis – lung, heart & retroperitoneal

Failure to Respond

- Wrong drug
- Inadequate dose or duration of therapy
- Inappropriate indicators of improvement
- Noncompliance

Failure to Respond

- Drug Interactions
- Wrong diagnosis

Advanced Parkinson's Disease

- Interferes with ADLs, mobility and speech
- Motor fluctuations
- Dyskinesia

Levodopa Pharmacology

- Short half-life
- Absorbed from small intestine
  - Gastric emptying
  - Large neutral amino acid transporter
- Saturable blood-brain barrier transport

Levodopa Pharmacology

- Duration of response is proportional to dosage size

Drugs That Augment Levodopa

- COMT Inhibitors
- Seligiline
- DA Agonists
- Amantidine

Sudden Loss of Response

- Intercurrent illness
- Subdural hematomas
- Poor compliance
- Prescription mistakes
- Drug interactions
  - Dopaminergic antagonists

Contraindicated Drugs

- Dopaminergic antagonists
  - Typical antipsychotics
  - Atypical antipsychotics
  - Antiemetics
- Non-selective MAO inhibitors
- Inhalational anethesia

Contraindicated Drugs

- Large doses of pyridoxine
- Iron preparations

Treating Autonomic & Systemic Complications

- Orthostatic hypotension
  - Fludrocortisone, Midodrine
- Urinary incontinence
  - Oxybutynin, tolteridine, propanthaline, Nocturnal desmopressin spray, hyoscyamine

Treating Autonomic & Systemic Complications

- Constipation
  - Stool softeners, bulk forming agents, laxatives, enemas
- Sexual dysfunction
  - Erectile agents, treatment of depression

VA Formulary Reminder

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VA Formulary Reminder

- Some drugs may be available through "VISN" formularies or non-formulary drug request process

Part II

Module 3

New Ways to do Old Things:

Maximizing Independence in Parkinson's Disease

Faculty:

Carol Maier Clerico, OT/L

Keith Robinson, M.D.

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Multidimensional Falling Risk Factor Modification

Keith Robinson, M.D., Physiatrist, Philadelphia PADRECC

Step #1 Identify the risk factors (refer to risk factors listed below)

Step #2 Identify an intervention to reduce each risk factor (refer to risk factors listed below)

Step #3 Put each intervention into practice: doctors, nurses, physical and occupational therapists, families, and patients.

Commonly Recognized Falling Risk Factors in the Elderly -- *Intrinsic Factors*

Risk Factor	Suggestions
Compromised mobility, strength, gait and balance	Exercise
Orthostasis, or decreases in blood pressure with positional changes	Stand up slowly
Polypharmacy, or the use of > 3 medications especially those necessary to treat high blood pressure, heart disease, insomnia, anxiety, urinary frequency, hallucinations and agitation	Minimize the doses and simplify the schedule
A history of stroke, heart failure, and arthritis especially in the neck and legs.	Medications and exercise
No participation in regular exercise or outside house work	Exercise
Compromised vision and hearing	Regular eye and hearing exams
Compromised peripheral proprioception or position sense	Supportive footwear and assistive devices such as canes and walkers
Foot disorders such as bunions and flat feet	Special footwear
Compromised cognition especially in attention and visual perceptual functions	Minimize environmental distractions, pacing, and visual scanning
"Fear of falling" syndrome	Exercise and supervised practice in threatening places

Commonly Recognized Falling Risk Factors in the Elderly-- *Extrinsic Factors*

Risk Factor	Suggestions
Non-level surfaces such as stairs and outdoors	Exercise and supervised practice
Unfamiliar environments	Use of assistive devices or another person until they become familiar
Poor lighting	Improve lighting particularly at night time
Objects on the floor including insecure floor coverings	Remove
Unstable furniture or railings	Repair
Improper use of assistive devices	Proper measurement, exercise and practice
Low toilet seat, bed and chairs	Raise the level so they are easier to get off and on
Improper footwear	Wear shoes that "hug" the feet and that have inserts that compensate for mal-alignment or deformities.

Falling Risk Factors in Parkinson's Disease

Risk Factor	Suggestions
Hallucinations or confusion associated with medication use	Minimize doses
Sleep disturbances associated with medication use	Minimize doses
Dyskinesias associated with medication use	Minimize doses
Use of cardiovascular medications	Minimize doses and simplify dosing schedules
Polypharmacy	Minimize doses and simplify dosing schedule
Compromised gait, posture, and balance	Exercise
Impaired vision	Regular eye exam
Orthostasis	Stand up slowly
Rigidity and bradykinesia	Medications and exercise
Freezing of gait	Medications, exercise, pacing and cueing strategies
More severe disease	Medications
Impaired hand and foot agility	Medications and exercise
Inability to arise from a chair	Exercise
Daily alcohol use	Minimize use
Depression and anxiety	Medications and counseling or psychotherapy
Cognitive impairments	Minimize distractions in the environment, pacing, and visual scanning

Environmental modification to reduce falling risk

1) Increase the height of seating surfaces including chairs, beds, toilet seats.
2) Remove loose rugs.
3) Improve lighting including nightlights.
4) Install grab bars near the toilet, in the shower and tub.
5) Use bedside commodes or portable urinal bottle for night-time elimination.
6) Create safer non-level surfaces: stair glides, ramping, 1-floor living space.
7) Obtain training and proper measurement in physical therapy when starting to use canes, walkers and wheelchairs.

Occupational Therapy Perspective

Carol Maier Clerico, OT/L, Therapy Education Coordinator
University of Virginia Health System

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Web sites of interest:

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www.promotingexcellence.org
www.partnershipforcaring.org
www.apdaparkinson.com
www.parkinsons.org.uk
www.pdf.org
www.nfcacares.org
www.caregiving.org
www.ninds.nih.gov/health_and_medical/disorders/parkinsons_disease.htm
www.cerebreon.com

Program Website

www.sahp.vcu.edu/gerontology/UMPDVidconference

Multidimensional Falling Risk Factor Modification

- Identify the risk factors
- Identify an intervention to reduce each risk factor
- Put each intervention into practice: doctors, nurses, physical and occupational therapists, families, and patients.

Falling Risk Factors in the Elderly: Intrinsic Factors

- Compromised mobility, strength, gait and balance: exercise
- Orthostasis, or decreases in blood pressure with positional changes: stand up slowly
- A history of stroke, heart failure, and arthritis especially in the neck and legs: medications and exercise

Falling Risk Factors in the Elderly: Intrinsic Factors

- Polypharmacy, or the use of > 3 medications especially those necessary to treat high blood pressure, heart disease, insomnia, anxiety, urinary frequency, hallucinations and agitation: minimize the doses and simplify the schedule
- No participation in regular exercise or outside house work: exercise

Falling Risk Factors in the Elderly: Intrinsic Factors

- Compromised vision and hearing: regular eye and hearing exams
- Compromised peripheral proprioception or position sense: supportive footware and assistive devices such as canes and walkers
- Foot disorders such as bunions and flat feet: special footware

Falling Risk Factors in the Elderly: Intrinsic Factors

- Compromised cognition especially in attentional and visual perceptual functions: minimize environmental distractions, pacing, and visual scanning
- "Fear of falling" syndrome: exercise and supervised practice in threatening places

Falling Risk Factors in the Elderly: Extrinsic Factors

- Non-level surfaces such as stairs and outdoors: exercise and supervised practice
- Unfamiliar environments: use of assistive devices or another person until they become familiar
- Poor lighting: improve lighting particularly at night time
- Objects on the floor including insecure floor coverings: remove

Falling Risk Factors in the Elderly: Extrinsic Factors

- Unstable furniture or railings: repair
- Low toilet seat, bed and chairs: raise the level so they are easier to get off and on
- Improper footware: shoes that "hug" the feet and that have insert that compensate for malalignment or deformities
- Improper use of assistive devices: proper measurement, exercise and practice

Occupational Therapists Focus On:

- Emphasizing functional independence
- Acknowledging the significance of routine tasks
- Valuing the daily activities that give life meaning & purpose

Occupational Therapists Focus On:

- Evaluating changing occupational roles & responsibilities with disease progression
- Enabling the individual and family to:
  - Anticipate care problems
  - Compensate for functional deficits
  - Work against the indirect effects of disease progression

Increasing Safety During Functional Activity

- Assistance with self care
- Evaluating adaptive equipment and techniques
- Planning for activity during more functional times
- Slowing the decline of independence as disease progresses

The OT Can Also Help

- Incorporate compensatory strategies into daily tasks
- Value the meaning & purpose of activity (and inactivity)
- Plan for and live through the later stages of the disease
- Help families provide care & ease the burden of caregiving

Incorporating Compensatory Strategies into Daily Tasks

- Motor and sensory strategies
  - Environmental modification
  - Motor techniques
- Behavioral cognitive strategies
  - Assistive technology
  - Consistency of routine

Valuing Meaning & Purpose in Activity & Inactivity

- Physical and emotional manifestations of advancing disease may compromise independence
- Individuals need to focus their energies on activities with meaning and purpose
  - Work
  - Leisure and social activities
  - Family
  - Reflection and remembrance

Helping Families Provide Care & Easing the Burden of Caregiving

- Coping with resistance to changing routines
- Assessing differing family roles and responsibilities
- Understanding the need for cohesion among family members
- Exploring family demographics
- Defining caregiver responsibilities
- Assisting with long-distance care giving
- Promoting caregiver "self care"

OT Assistance During Earliest Stages of Disease

- Education about the importance of planning ahead
- Education about the benefits of daily participation in activity
- Performance of those tasks that sustain independence and maintain good functional mobility

OT Assistance For Mild Impairment

- Assistive devices and techniques
- Balance training
- Safety awareness
- Postural awareness
- ROM and stretching

OT Assistance For Mild Impairment

- Fine-motor skills
- Functional mobility and transfers
- Energy conservation
- Skin care

OT Assistance For Moderate Impairment

- Positioning and safety assessment
- Equipment recommendations
- Balance awareness during ADLs
- Family training regarding assistance with ADLs and functional mobility

OT Assistance For Severe Impairment

- Transfers and positioning
- Body mechanics during care giving
- Seating and positioning needs
- Assisting with palliative care and end of life care planning

Critical Components of Care Planning

- Involve the patient & family early in all planning
- Begin talking about safety issues from the first visit
- Discuss roles & establish an occupational history
- Plan for the future when discussing equipment, modification, assistance & placement
- Set realistic goals/limits

Part II

Module 4

Mind, Mood and Memory:

Cognitive and Behavioral Changes in Parkinson's Disease

Faculty:

Paul Moberg, Ph.D.

Daniel Weintraub, M.D.

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Mind, Mood, and Memory: Cognitive and Behavioral Changes in Parkinson's Disease

Paul Moberg, PhD, Neuropsychologist
Philadelphia PADRECC

Daniel Weintraub, M.D., Geriatric Psychiatrist
Philadelphia PADRECC

Importance of psychiatric complications in Parkinson's disease (PD)

- PD is a neuropsychiatric disorder - motor and non-motor symptoms
- Prevalent
- Mental suffering
- Affects quality of life
- Leads to caregiver burden and depression
- Complicates management of motor symptoms
- Associated with increased cognitive decline and mortality (but not suicide)

Major non-motor symptoms and disorders in PD

- Depression
- Anxiety
- Psychosis
- Affective lability
- Apathy
- Dis-inhibition
- Disorders of sleep and wakefulness
- Cognitive disorders

Depression

- Depression is common and extensively studied
- High but varying prevalence rates (5-50%)
- Population studied
- Major vs. non-major depression
- Persistence (brief reactive disorder)
- Symptom overlap (inclusive vs. etiologic criteria)

Diagnosis of depression in PD

- Lessons from diagnosing depression in AD (consensus criteria)
- Heterogeneity
- Anhedonia > mood disturbance
- Less guilt and self-blame
- Frequent non-motor co-morbidity (anxiety, apathy, psychosis, and cognitive changes [global, executive])
- No clear PD clinical correlates
- Important to interview caregivers or significant others

Cause of depression in PD

- Multiple factors
- Psychological reaction to chronic, disabling, progressive illness
- Same neurotransmitters and regions of brain affected in PD linked with mood

Treatment of depression in PD

- Antidepressants commonly used in PD
- Newer antidepressants
- Appear safe and well tolerated overall
- Many open-label studies reporting overall improvement in depression

Limitations in knowledge about treatment of depression

- Few placebo-controlled studies have been negative
- High placebo response rate
- Possibly lower antidepressant response
- Need to determine if there differences between antidepressants in PD
- Augmentation vs. switching
- Optimal dosages
- Duration of treatment before change

Other treatments for depression

- Psychotherapy
- Support groups
- ECT

Future directions

- Consensus on diagnostic criteria
- Larger, controlled treatment studies (pharmacotherapy, psychotherapy)
- Does treatment improve depression? Other non-motor symptoms? Quality of life?
  Function? Caregiver distress? Motor function?

Anxiety in PD

- Maybe higher than depression
- Often more upsetting
- Frequently co-exist

Manifestation of anxiety in PD

- Generalized
- Anxiety or panic attacks
- Relationship to off periods
- Social phobia

Treatment of anxiety

- Pharmacotherapy - newer antidepressants
- Benzodiazepines
- Psychotherapy not studied

Psychosis in PD

- 20-40%
- Primarily visual disturbances or hallucinations
- Can be both hallucinations and delusions

Etiology of psychotic symptoms

- Associated with all PD medications
- More common with cognitive impairment

Distress secondary to psychosis

Variable insight
Can be part of behavioral disturbance
Associated with nursing home placement

Treatment of psychosis in PD

Re-evaluate PD regimen (levodopa last), risk: benefit ratio
All antipsychotics can worsen Parkinsonism
Clozapine best tested and causes the least Parkinsonism, difficult to use
Newer antipsychotics better than older ones
Quetiapine -- medication of choice currently
Lower dosages used than in non-PD patients

Affective lability in PD

Affective or emotional lability, also called pseudobulbar affect
Reported in numerous neurodegenerative diseases
Usually tearfulness, uncontrollable, disconnected, change from previously
Associated with impairment in neural circuits servicing frontal lobes
Treat with antidepressants (TCA's, SSRI's) or mood stabilizers

Apathy in PD

Apathy also common in neurodegenerative diseases
Decrease in goal-directed behavior, cognition (amotivation), and emotion
Distinct from depression
Also associated with frontal lobe impairment
No clear treatment, stimulants most commonly used

Dis-inhibition in PD

Loosely defined term
Overlap with compulsive behavior
Gambling, sexual addiction, poor judgment, impulsiveness
Related to PD meds (dopamine agonists)
Should discontinue offending medication
Also use newer antidepressants, mood stabilizers

Disorders of sleep and wakefulness in PD

Sleep-related disorders
Covers many different disturbances
Sleep pattern is disrupted secondary to neurodegeneration, increase in motor symptoms
Insomnia common complaint
Daytime fatigue (disease vs. medication)
Periodic leg movement disorder, related to restless legs syndrome
REM behavior disorder
Treatment includes change in bedtime PD meds, use of sedative-hypnotics and other sleep medications (trazodone), dopamine agonists, stimulants (modafinil)

Conclusion

PD is a neuropsychiatric disease with broad range of psychiatric disturbances
Important to assess due to impact on quality of life, function, and long-term outcome
Further research needed to better characterize the specific disorders and to determine the optimal treatments for them

Disorders of Sleep & Wakefulness

- Insomnia
- Periodic Leg Movement Disorder/ Restless leg Syndrome
- REM Behavior Disorder
- Fatigue
- Excessive Daytime Sleepiness

Risk Factors for Dementia in PD

- Increasing age
- Older age at PD onset
- Longer disease duration
- Family history of dementia
- Greater severity of motor symptoms

Risk Factors for Dementia in PD

- Depression
- Hypertension
- Low socio-economic status
- Limited educational attainment
- Poor medication tolerance (i.e., confusion or psychosis accompanying administration of dopaminergic agents)

Neuropsychological Deficits in PD

- Complex attention
- Executive functions
- Information retrieval
- Procedural memory
- Visuoconstruction
- Word-list generation (Fluency)
- Speed of information processing

Internally-Generated Strategies

- Keep a detailed diary or "memory book"
- Keep paper and pen handy to write down to be remembered information
- Organize lists into categories to stimulate memories

Internally-Generated Strategies

- In conversation, focus on remembering main points, not trying to recall every detail
- When performing tasks, minimize distractions and perform one task at a time
  (i.e., avoid multi-tasking)

Externally-Generated Strategies

- Allow the PD patient ample time to comprehend and process what has been said and to respond
- In speech, be concise when speaking of specific people and events
- When presenting the patient with a choice, avoid open ended questions, instead providing limited options

Externally-Generated Strategies

- Maintain consistent and strong routine on a daily basis. That is, perform activities of daily living in the same order and way every day
- Review upcoming activities for the day every morning

Part III

Module 5

Surgical Intervention in Parkinson's Disease

Faculty:

Susan Heath, M.S., R.N., CNRN

William J. Marks, Jr., M.D.

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Treatment of Parkinson's Disease

- Pharmacotherapy
- Rehabilitation
- Surgical Therapy

Limitations of Medications

- Control of symptoms wanes as PD progresses
- Disabling motor complications may develop
  - Wearing off of symptomatic effect
  - Development of dyskinesia
  - Fluctuations in motor function

Limitations of Medications

- Medications, especially at higher doses, produce adverse effects
  - Dyskinesia
  - Psychiatric & cognitive symptoms
  - Gastrointestinal, autonomic, & other problems

Historical Notes

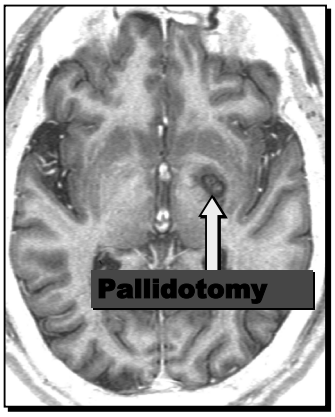
- 1950s: Thalamotomy & pallidotomy commonly used to treat symptoms of PD
- 1990s: Shortcomings of medication & advances in functional neurosurgery techniques leads to a renewed interest in surgical treatment

Historical Notes

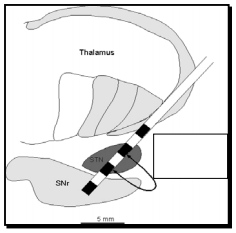
- 2002: FDA approves DBS of globus pallidus and subthalamic nucleus to treat Parkinson's disease symptoms

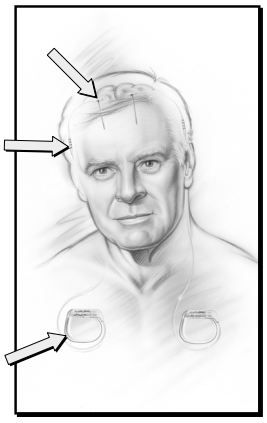
Surgical Treatment of PD

- Ablative procedures
  - Thalamotomy
  - Pallidotomy
- Deep Brain Stimulation (DBS)
  - Thalamus (Vim)
  - Subthalamic nucleus (STN)
  - Globus pallidus (GPi)



Deep Brain Stimulation





Advantages of DBS Over Ablation

- Non-destructive
- Reversible
- Adjustable
- Safer for bilateral use

Disadvantages of DBS

- Risks of implanted device
- Needs access to programming
- Finite battery life of generator
- Cost
- Cosmesis

Candidates for Surgery

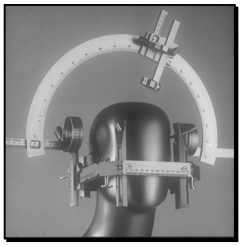
1. Idiopathic Parkinson's disease
2. Despite optimized medication regimen, patient has disabling motor symptoms
3. Continued response (even brief) to levodopa

Candidates for Surgery

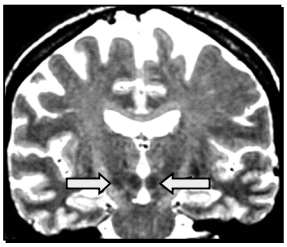
4. Cognitively intact, depression treated, medically stable
5. Realistic expectations, disease insight, and supportive home environment

Surgical Technique

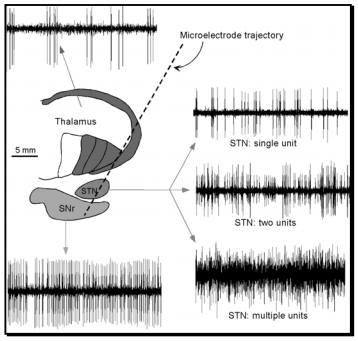
Stereotactic Head frame



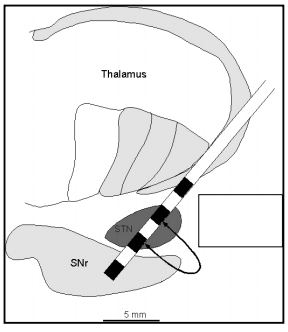
MRI Targeting of STN



Brain Mapping



Intra-Op Test Stimulation



Complications

- Hemorrhage
  - 1-2%
  - May be symptomatic or silent
  - Risk for ablative & DBS surgery
- Infection
  - 3-5% for DBS
- Hardware malfunction

Post-Operative Management

- Average hospitalization 3 days
- Patient's symptoms may transiently improve (even though DBS not yet activated)
- Effects of stimulation explored
- Patient education

Ongoing Care

- Stimulators activated 1-30 days after surgery
- Stimulators adjusted over the course of several months
- Benefits of stimulation often take time (hours to days) to accrue after a change in stimulation is made

Ongoing Care

- Medications reduced whenever possible; 50% decrease in levodopa requirements often possible

Expected Outcomes: DBS for PD

- DBS of thalamus only suppresses contralateral tremor
- DBS of subthalamic nucleus or globus pallidus suppresses contralateral tremor, rigidity, bradykinesia, & gait disturbance

Expected Outcomes: DBS for PD

- With DBS, OFF-medication motor function becomes more like the best pre-op ON-state
- OFF time is reduced
- Dyskinesia is reduced
- Motor fluctuation is lessened

Part III

Module 6

Current Parkinson's Disease Research and Hope for the Future

Faculty:

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Elizabeth Protas, P.T., Ph.D., FACSM

An electronic copy of the handout and Power Point slides are available at no charge. Please visit the Virginia Geriatric Education Center website at www.sahp.vcu.edu/gerontology/ or the national PADRECC website at www.va.gov/PADRECC to download this information.

Current Parkinson's Disease Research and for the Future

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Objectives:

1) Describe the recent advances in Parkinson's disease (PD) research, including genetics, environmental factors, new treatments, pathogenesis, and gene therapy.
2) Learn how gene mutations can cause familial PD.
3) Discuss some environmental factors implicated in PD.
4) Review several promising new drugs that are undergoing clinical trials.
5) Discuss some research on non-pharmacological therapies.
6) Consider other novel treatments of PD.
7) Review research activities at VA Parkinson's Disease Research, Education and Clinical Centers (PADRECCs).
8) Discuss new information regarding the pathogenesis of PD.
9) Outline future research and hope.

Outline:

I. Introduction of flourishing research activities in PD
II. Familial PD and genetics
    i. Twin study
    ii. Gene mutations causing PD
    iii. Contribution of genetics to the cause of PD
III. Environmental factors
    i. Rural living / farm work
    ii. Coffee or tobacco use
    iii. Pesticides and herbicides
    iv. Neurotoxins
IV. New medical treatments under study
    i. Dopamine agonists
    ii. Monoamine oxidase B inhibitors
    iii. Neuroprotective agents
V. Non-pharmacological therapies
    i. Cueing to improve gait
    ii. Supported treadmill training
    iii. Exercise programs

VI. Novel treatments under study
    i. Cell transplant
        1. Fetal cell transplant
        2. Retinal pigment epithelial cell transplant
    ii. Neurotrophic factor GDNF infusion
    iii. Gene therapy
VII. Research at VA PADRECCs
VIII. Pathogenesis of PD
    i. Both genetic and environmental factors contribute
    ii. Ubiquitin-proteasome system
    iii. Mitochondrial dysfunction
    iv. Oxidative stress
IX. Hope of the future
    i. Improve treatments for the most disabling symptoms
    ii. Brain stimulation, gene therapy, stem cell therapy
    iii. Finding the cause(s)
    iv. Aiming for the cure

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Recent Research in Parkinson's Disease

- Genetics
- Environmental effects
- New drugs
- Non-pharmacological therapies
- Gene therapy
- Neuroimaging
- Pathogenesis

Environment

- Rural living/farm work
- Coffee & tobacco
- Heavy metals
- Diet
- Pesticides/herbicides
- Drugs

Environment

- Pesticide - Rotenone
  - Dopaminergic degeneration
  - Parkinsonian symptoms
- MPTP
  - Rigidity & bradykinesia

New Drugs in Clinical Trials

- Rasagiline
- Sumanirole
- Remacemide
- Rotigotine
- KW-6002

New Drugs Under Development

- Neuroprotective agents
- Neurotropic factors

Non-pharmacologic Therapies

- Cueing
- Body-weight supported treadmill training
- Gait & step training
- Axial mobility
- Exercise

Novel PD Treatment

- Fetal cell transplantation
- Retinal pigment epithelial transplantation
- GDNF infusion
- Gene therapy

Possible Causes of PD

- Ubiquitin-Proteasome system
- Mitochondrial system
- Oxidative stress
- Environmental factors

Future Hope in Research

- Improving treatment
- More innovative therapies
- Understanding the pathogenesis of PD
- Finding a cure

Appendix A

Speech and Swallowing in Parkinson's Disease

Heather Evans, M.S. CCC-SLP, Richmond/Southeast PADRECC
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Systems of Speech Production Affected in Individuals with Parkinson's Disease (PD)

- Respiration
- Phonation
- Resonation
- Articulation

Respiration

- "Foundation of speech production"
- Shallow breaths
- Difficulty coordinating breathing and speaking
- All result in minimal speech output

Phonation

- Voicing - " Voice Box"/"Larynx"
- Vocal Cords - Abduct (open), Adduct (closed)
- Gracco and others (1994) reported aerodynamic evidence of an increase in vocal tract resistance in an individual with PD suggesting an increase of glottal or supraglottal muscle tension. [1]

Resonation

- Individual with PD may present with nasal voice quality due to velum not adequately moving, allowing air to leak into the nose.
- Hoodin and Gilbert (1989) did find increased nasal airflow in a study of individual with PD.[1]
- X-ray microbeam assessment of a small number of PD individuals have demonstrated reduced degree and velocity of velar movements during repetitive utterances (Hirose, Kiritani and Swashima, 1982b; Hirose and others 1981).[1]
-

Articulation

- Articulatory system comprised of muscles of face, lips, tongue and jaw
- Reduced range of motion
- Reduced speed of articulatory movement
- Weismer (1984) considers spirantization of stops a unique characteristic of Parkinson's dysarthria.[1]
- Logemann and others (1978), found predominance of highly consistent manner errors that occurred most frequently for stops, fricatives and affricatives. 1

Hypokinetic Dysarthria: Characteristics of Voice

- Monotone
- Reduced loudness
- Breathy vocal quality, some with tremor
- Imprecise articulation, may be mumbled or slurred
- Palilalia (compulsive repetition of syllables)
- Increased rate
- Short rushes of speech
- Hanson, Gerratt and Ward (1984) documented several laryngeal abnormalities (30/32) patients with PD including vocal cord bowing. 1

Speech Therapy Goals

- Increase motor musculature strength to aid against further deterioration of speech function
- Improve respiratory support for speech production
- Increase speech intelligibility through compensatory techniques in order to maximize communicative effectiveness

Strategies that can enhance speech

- Quiet environment
- Speak slowly, loudly and clearly
- Look at the person to whom you are speaking
- Well lit room
- Use short phrases
- Over-articulate
- Good posture
- Vocal rest
- Don't rush or force conversational responses
- When you are talking, try to use shorter sentences 4
- Before starting to speak, swallow all excess salvia in your mouth 4
- Make sure the lips meet firmly for b, p and m sounds 4
- Try to "explode" the sounds t, d, k, and g. 4
- Pause between words and remember to keep your volume up until the end of your sentence. 4
- Speak for YOURSELF!!

Lee Silverman Voice Treatment --- *Helping individuals with Parkinson's disease "keep their voices alive"*

What LSVT is . . .

- The first treatment effective for treating voice and speech disorders associated with Parkinson's disease.
- An intensive program that enhances speech intelligibility through improved loudness, voice quality and articulation.
- A behavioral treatment based on modification of underlying laryngeal dysfunction including problems with vocal cord adduction and generation of a stable voice
- A treatment for the underlying physical pathology associated with voice disorders of Parkinson's disease.
- A treatment scheduled for four days per week for four weeks – 16 sessions with additional practice outside of treatment setting.
- A method that shows improvement from pre- to post-treatment in 90% of patients

- A method that helps 80% if those patients maintain improvement for 12 to 24 months post treatment.

How LSVT works…

Therapy is based on 5 essential concepts:

1. Focus on VOICE (increase/improve vocal fold adduction)
2. Focus on HIGH EFFORT (phonatory and physical)
3. Focus on INTENSIVE TREATMENT (16 sessions in one month)
4. Focus on CALIBRATION (loudness habituation and carryover)
5. QUANTIFICATON (motivation, feedback, objectively measure success)

- Hierarchical speech loudness drills
- Integration of five essential concepts-all are completed daily and quantified for the greatest measure of success
- Techniques used are common voice treatment approaches, but LSVT emphasizes administration and integration of techniques specifically design for speech and voice disorders associated with PD
- Available only through specially trained and certified LSVT therapists. To find an LSVT therapist in your area, contact the LSVT website: www.lsvt.org

Sample of LSVT exercises:

1) **Take a deep breath and say the "ah" sound in a loud voice.**
   Try projecting your voice across the room.
   Hold the "ah" for as long as you can.

2) **Sing musical scales on "la" both going up and coming down.**
   Make sure to take a deep breath before starting, and sing in a loud voice.

3) **Try talking in a voice that feels/sounds really loud.**
   This increases overall function of your voice and speech.

4) **Practice using a loud voice.**
   Start in short phrases, then sentences, then reading paragraphs, and finally in conversations.
   Although your voice sounds loud to you, it is probably just right for the listener.

5) **When speaking on the phone engaged in conversation, count the number of times you are asked to repeat.**
   Now try again in a loud voice, and count the requests to repeat.
   Doing this helps increase awareness of how you actually sound to others.

6) **While driving or riding in the car, practice saying aloud the street signs or places you pass.**
   Use a loud voice.

7) **Read short newspaper articles out loud.**
   Read each article as if you were reading to a large group.

8) **Read children's books to your children or grandchildren in a loud voice**.
   Add extra expression into your voice as you read.

9) **Tape record yourself while doing any of the above exercises**.
   This helps increase awareness of how you sound when using a strong voice.

Practice Maneuvers

Practice the following phrases in a loud, expressive voice:

"Shut the door'	**"Good night, honey"**
"Pass the food, please"	**"Answer the phone."**
"How are you?"	**"I'm fine, thank you."**
"I love you."	**"Who is this?"**
"I need help!"	**"Please sit down."**

Practice saying the following sentences in a loud, strong voice: Use proper breathing techniques as indicated to enhance vocal strength:

1)	(inhale)	"Did I take my medication yet?"	(exhale)
2)	(inhale)	"I would love a cup of coffee."	(exhale)
3)	(inhale)	"Where are you going?"	(exhale)
4)	(inhale)	"I need to go to the bathroom."	(exhale)
5)	(inhale)	"It's a beautiful day!"	(exhale)
6)	(inhale)	"Where is the remote control?"	(exhale)
7)	(inhale)	"Would you like to go out to eat?"	(exhale)
8)	(inhale)	"It's good to see you."	(exhale)
9)	(inhale)	"How are you today?"	(exhale)
10)	(inhale)	"I went to the doctor's last week."	(exhale)

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Parkinson's Dysphagia

Dysphagia (difficulty chewing and swallowing) is not uncommon in patients with PD and can be characterized by one or all of the following:

- *Difficulty controlling the bite or sip within the mouth*
  Inability to form a cohesive bolus or ball of food or liquid within the mouth; liquid spilling out of mouth; pocketing of food or liquid in cheek area; material spilling into the back of the throat before ready to swallow

- *Difficulty moving the bite or sip from the front to the back of the mouth*
  Disorganized, ineffective tongue movement; lingual pumping; increase in time it takes to consume food or liquid; may need multiple swallows

- *Difficulty initiating a swallow*

Delayed swallow; impaired sensation; slowness of muscles of throat; may cough or choke when drinking liquid or when swallowing saliva or secretions

- *Weakened movement of the throat muscles*
  Stiffness of the throat muscles; residue in throat after swallowing is completed; complain of something being "stuck in their throat"

Signs and Symptoms of Dysphagia*

- Coughing while eating or drinking during meal or immediately after meal
- Change in vocal quality - "wet" or "gurgly"
- Throat clearing during or after eating
- Increased congestion after eating
- Increased length of time or increased effort required to eat meals
- Weight loss or dehydration
- Complaint of food being "stuck in throat"
- Liquids required to "wash down" solids
- Low grade fever for unknown reason
- Pneumonia

*Although a patient may deny a swallowing disorder, the reports may be inaccurate. This lack of awareness is particularly prevalent in neurologically impaired patients, e.g. those with CVA, PD, or multiple sclerosis.[3]

Goals of Dysphagia Therapy

- Improve the function of affected muscles through exercise.
- Prevent the rate and degree of decline in swallowing function through exercise
- Teach compensatory strategies designed to make swallowing safer

Techniques to make eating easier and safer 4

- Sit upright during all eating and drinking or taking pills
- Tilt head slightly forward, not backward as you swallow
- Take small bites of food and chew thoroughly. Don't add any more food until the first bite has been swallowed
- Take small sips of liquid. Hold in your mouth for a short time to prepare yourself for swallowing.
- Don't use straws.
- Move the food backward in your mouth with your tongue.
- "Double swallow" (swallow a second time) if you feel that food did not go down completely after the first swallow. Taking a sip of liquid between bites of food can help.
- If eating one big meal is very tiring, try several smaller meals spaced out during the day. Nutritional supplements during the day may be helpful in keeping calorie count high enough for good energy level.
- If coughing or choking occurs, lean forward and keep your chin tipped downward while you cough.

Dietary tips to make eating easier and safer 4

Consider selecting the following types of foods:

- Moderate textured wheat breads
- Oatmeal, cream of wheat or moistened dry cereals
- Well cooked, tender chicken, turkey, fish without bones, chopped and ground meats
- Soft casseroles or scrambled eggs instead of fried eggs
- Mashed potatoes or rice moistened with gravy instead of wild rice or french fries

- Soft, cook pasta elbows instead of long, dry spaghetti
- Soft, well cooked, cut up vegetables instead of raw vegetables.
- Pureed or mashed fruits or fruit juices instead of fruits with seeds or hard outer skins.
- Custard, yogurt, ice cream or other soft desserts, without pineapple, nuts, seeds or coconut.

Exercises for Improving Swallowing

- Oral motor exercises
- Masaka maneuver
- Open your mouth, smile and then swallow
- Say "Ung-Guh"
- Say "ah" and hold for at least 10 seconds
- Say "ah ah ah" while tightening throat muscles

Exercises should be done 10 times each, 3 times per day.

Although initially patient may be too weak to perform this many, strength should steadily increase to improve performance.

Improving Swallow Function 2

The following guidelines and tips are provided for improving eating, chewing and swallow abilities:

- **"Think Swallow"-** Remember to swallow saliva before speaking and otherwise frequently to compensate for the reduction of the natural reflex.
- **Swallow twice after every bite**. **Take small bites.**
- **Take small sips. Alternate bites and sips.**
- **Be wary of straws**. Straws are useful when someone has severe tremors or dyskinesias. Do not put the straw too far back in the mouth.
- **Do not talk with food in your mouth.**
- **Keep your chin down or parallel to the table.** When the chin is raised, the esophagus is partially closed off and the trachea is more open. This position increases the risk of aspiration.

Dysphagia Diets

- What you swallow is just as important as how you swallow. No swallowing program will be effective unless the primary goal of complete nutrition and hydration is achieved.
- If a patient is having difficulty swallowing, a Modified Barium Swallow study may be performed. This test allows the SLP and a radiologist to see where the difficulty is occurring, how changes in positioning and consistency of food affect swallowing, and if aspiration is occurring.

A patient with PD may be placed on a dysphagia diet for two reasons

- To compensate for swallowing difficulty
- To avoid risk that food could be aspirated into the airway or cause an obstruction of the airway

A dysphagia diet will recommend the safest consistency of liquids and solids for the patient to prevent aspiration.

Liquids:

- Thin: clear liquids with little or no body such as water, coffee, tea, broth
- Thickened: liquids with body that can be adjusted to 3 consistencies: nectar (like tomato juice), honey, pudding
- Thickener is modified corn starch
- Thickener changes the consistency but not the taste
- Takes 2-4 minutes of stirring to achieve proper consistency
- Allow carbonated drinks to settle a little before putting in thickener

Solids/Purees:

- Puree diet: all items that are smooth, blenderized and do not require chewing
- Mechanical soft diet: soft foods that are chopped to the size of the nail on your finger
- Soft diet: all food items are soft enough to chew easily; small bites recommended
- Regular diet: all types and sizes of foods are appropriate

Dysphagia Severity Rating Scale for Parkinson's Disease

Waxman and colleagues (1990) have proposed a Dysphagia Severity Rating Scale for staging purposes. The authors utilize a seven-point scale ranging from "normal swallowing mechanism" to "severe dysphagia". Gradations in the rating of severity are based on the patient's report, observations of family members or caregivers, and the result of a radiographic examination.5

Rating	Description
7	***Normal Swallowing Mechanism***
6	***Minimal Dysphagia:*** Videofluoroscopy shows slight deviance from a normal swallow. Client may report a change in sensation during swallow. No change in diet is required.
5	***Mild Dysphagia:*** Oropharyngeal dysphagia is present but can be managed by specific swallowing suggestions. Slight modification in consistency of diet may be indicated.
4	***Mild-Moderate Dysphagia***: Potential for aspiration exists but is diminished by specific swallowing techniques and a modified diet. Time required for eating is significantly increased, and supplemental nutrition may be indicated.
3	***Moderate Dysphagia:*** Significant potential for aspiration exists. Trace aspiration of one or more consistencies may be seen under videofluoroscopy. Patient may eat certain consistencies by using specific techniques to minimize potential for aspiration or to facilitate swallowing. Supervision at mealtimes required. Patient may require supplemental nutritional orally of via tube feeding.
2	***Moderate-Severe Dysphagia:*** Patient aspirates 5 to 10 percent on one or more consistencies, with potential for aspiration of all consistencies. Potential for aspiration minimized by use of specific swallowing instructions. Cough reflex absent or nonproductive. Alternative mode of feeding required in order to maintain patient's nutritional needs. If pulmonary status is compromised, "nothing by mouth" may be indicated.
1	***Severe Dysphagia:*** More than 10 percent aspiration for all consistencies. "Nothing by mouth" recommended.

Good Prognostic Indicators for Patients with Dysphagia

- The patient's comprehension and understanding skills are intact
- The patient can self-monitor and self-correct
- The patient has a supportive family that will help with the strategies
- The patient has a strong cough reflex
- Little or no pharyngeal/esophageal dysphagia

Early Intervention
As with any progressive neurological condition, early intervention is the key to maintaining or increasing communicative effectiveness and swallow function. As soon as an individual with PD or care partner notices changes in speech or swallowing, it is time to seek referral to a SLP. It is much easier to learn effective strategies and techniques to keep the speech mechanism highly functional than it is to rebuild what may have already been lost. 2

To locate a Speech-Language Pathologist in your area
Contact the American Speech-Language and Hearing Association (ASHA)
10801 Rockville Pike, Rockville, Maryland 20852
Phone: (800) 638- 8255

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PARKINSON RESOURCES ON THE WORLD WIDE WEB:

American Parkinson Disease Association	**www.apdaparkinson.com**
Michael J. Fox Foundation	**www.michaeljfox.org**
National Parkinson Foundation	**www.parkinson.org**
Parkinson Disease Foundation	**www.pdf.org**
Parkinson's Information	**www.parkinsoninfo.com**
People Living with Parkinson's (PLWP, Inc.)	**www.plwp.org**
World Parkinson Organization	**www.wpda.org**

Appendix B

Quality of Life in Parkinson's Disease: A Selected Reading List

Naomi Nelson, Ph.D.
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Appendix C

Nutrition and Parkinson's Disease

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Nutrition intervention/Medical Nutrition Therapy (MNT) has an important role both potentially in risk-reduction for Parkinson's disease (PD) and in the therapeutic support and treatment in all stages of PD. Dietitians play a key role in helping patients with PD optimize their nutritional status and manage various nutrition-related symptoms and medication side-effects. Good nutrition, adequate hydration, along with regular exercise – are essential to the overall management of PD.

Parkinson's disease is characterized by a severe shortage of dopamine. Dopamine is a chemical substance, produced in the brain that enables people to move normally and smoothly. Dopamine deficiency causes the symptoms of Parkinson's disease including tremor, impairment balance and coordination, and slowing of movements.

Parkinson's Disease can slow the gastric motility, causing constipation. Swallowing is prolonged; the stomach takes longer to empty and food travels through the intestines slowly. It can also lead to loss of the sense of taste, and of smell. People with Parkinson's disease are at risk for malnutrition, constipation, dehydration, weight loss, and bone fractures.

1) Constipation is a common occurrence in PD, especially later in the disease. Constipation is defined as having fewer than three bowel movements per week. PD may cause some degeneration of the nerves of the GI tract and cause constipation. PD medications can also lead to constipation. Constipation can interfere with the uptake of drugs such as levodopa. Eating a diet high in fiber and fluids can reduce constipation.

2) Adequate fluid intake is important to prevent dehydration. Many PD medications also "dry out" the body. It's important to drink plenty of liquids in order to enhance the absorption of both nutrients and medications.

3) Attaining and maintaining a desirable weight is very important. For underweight patients, frequent, small meals may help maintain optimal weight. Oral medical nutrition supplements can be helpful. For overweight patients, moderate caloric and fat restriction can contribute to overall health goals.

   * Weight loss is common among PD patients. PD patients are four times more likely to have a reported weight loss of greater than 10 pounds compared to control subjects. The weight loss is correlated with the stage of the disease.

4) Studies have shown that both men and women with PD are likely to have lower bone mineral density, and greater incidence of osteoporosis, fall and bone fractures.

Eating a healthy, plant-based, nutrient rich diet can help a person with PD maintain optimum health and may help reduce risk for PD. However, fiber, calcium/Vitamin D, protein and medication – deserve special attention.

a) Fiber- At least 20-25 grams of fiber per day is recommended. If patients experience frequent constipation, 30-35 grams/day should be consumed. Fiber–rich foods include whole grains, bran, cooked, dry beans, and fruits and vegetables with edible skin. If bloating and gas occur while eating fiber-rich foods, over-the-counter products like Beano™may help.

b) Calcium/Vitamin D- lack of calcium/vitamin D can lead to brittle bones and to an increased risk for fractures. This is especially dangerous in PD, where falling is more common because of gait and balance impairment. Adequate intake of calcium and vitamin D help prevent loss of bone density. Adequate, but not excessive intake of dairy products may be important. One study shows that higher intake of dairy products may increase the risk of PD in men, but not in women.

c) A small percentage of patients with PD need to alter the amount or timing of protein intake when on PD medications. Medications used to treat PD can cause nausea and appetite loss. The medications levodopa and carbidopa/levodopa " Sinemet " are most effective if taken on an empty stomach (30-45 minutes prior to eating) and with 4-5 oz of non-dairy fluid. Because levodopa is an amino acid (amino acids are the building blocks of protein), it competes with the amino acids of dietary protein for absorption. This competition may prevent full absorption of levodopa, and reduce the efficacy of levodopa therapy. In extreme cases, the majority of protein can be consumed at the evening meal.

d) Levodopa may precipitate elevated *homocysteine*, a substance in the blood that is associated with coronary disease, stroke, congestive heart failure, cognitive decline, and Alzheimer's disease. A diet rich in the B vitamins, especially folic acid, or a B-vitamin supplement can help reduce homocysteine levels. Foods rich in folic acid include green leafy vegetables, dried peas and beans, citrus fruits and whole grains.

e) A recent study has showed that dietary vitamin E (vitamin in food i.e. nuts, seeds, salad oil/dressing and plums, NOT vitamin E supplement) appears to reduce the risk for PD. (Brain penetration of vitamin E may be greater when taken in naturally occurring dietary forms.)

f) Co-enzyme Q10 supplement may also help to slow the progression of PD. According to one study, the benefit was greatest in subjects receiving the higher dosage of up to 1200 mg/d. Larger studies are needed in order to confirm these results. It should be noted that possible side effects of CoQ10 include insomnia, nausea, and dizziness.

Guidelines for Nutrition Information/Instruction

Introduction: The health care team shares responsibility for promoting, providing and monitoring the effectiveness of an appropriate level of nutrition education for patients diagnosed with Parkinson's disease. Nutrition education involves two levels:

Level 1: The provision of basic nutrition education for patients with interest and/or identified low risk health needs.

Level 2: The provision of Medical Nutrition Therapy for patients with identified significant health/nutrition risk.

Medical Nutrition Therapy (MNT) is an intervention provided by registered dietitians, often with assistance from a dietetic technician.

MNT includes nutrition assessment and intervention with appropriate selected modalities (ADA, 1995). Nutrition assessment involves assessment of the nutrition status of:

- individuals with a condition, illness, or injury that puts them at risk
- healthy, at risk individuals for preventive measures

It includes a review and analysis of

- medical, social, and medication history
- nutrition and diet history
- laboratory values
- anthropometric measurements

Intervention involves the selection of nutrition and other related modalities most appropriate to manage the condition, treat the illness and injury, or initiate preventive measures. These include:

- nutrition skills development and counseling leading to the development of a personal nutrition and lifestyle plan to achieve nutritional goals and desired health outcomes.
- specialized nutrition therapies such as supplementation with special medical nutrition foods for those unable to obtain adequate nutrients from food intake alone. These include oral liquid supplements, enteral nutrition delivered via tube feeding for those unable to ingest or digest food.

Level 1 Basic Nutrition Education for Patients with low or marginally high body mass index

Target Population: Patients with BMI between 21 and 27 or those who express interest in health risk reduction.

The content of Level 1 basic patient/family education will include the following:

- High Fiber, plant-based diet
- Adequate calcium and vitamin D
- Adequate intake of nutrient -dense foods
- Adequate hydration
- Daily foods that are rich sources of Vitamin E, folate

Level 1 Basic Education Providers: Level 1 basic education may be provided by a RPh, RN, LVN, MD, PA, NP or DTR

Examples of Materials/Methods that May Be Used: Instructional sheets – either available on-line/Intranet nutrition education materials such as The Food Pyramid, and Enjoy the Taste of Eating Right, Best Food Sources for Vitamins/Minerals, Water, the most over looked Nutrient, Eating a High Fiber Diet and Boost Your Nutrition.

Outcome Measures: Use open-ended questions to evaluate the patient, family and/or caregivers ability to identify and describe appropriate food choices and/or assist in medical management of Parkinson's.

Documentation (VA Staff): CPRS progress note to include provision of instructional sheet and patients, families and/or caregivers level of understanding. Any nutrition referral/consult should be incorporated into the PN plan.

Consider referral for Level 2 MNT:

- BMI < 21
- Evidence of unconventional nutritional therapies that exacerbate malnutrition (e.g. recent significant weight loss)
- Existence of co-morbid chronic disease (e.g. diabetes, CAD, COPD, hypertension or cancer).
- For symptom control (constipation, poor appetite)
- Need for enteral nutrition support (e.g., PEG tube feeding)

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Appendix D
Overview of PADRECC

In 2001, the Veterans Health Administration, one of three major branches in the Department of Veterans' Affairs (VA) created six Parkinson's Disease Research, Education and Clinical Centers (PADRECCs) in an effort to improve care for veterans suffering from Parkinson's disease and to pursue a cure for this condition. The centers are located in Philadelphia, Richmond, Houston, Portland/Seattle, San Francisco and West Los Angeles.

The PADRECC offers a variety of clinical and educational programs as well as research opportunities for veterans who have been previously diagnosed with Parkinson's disease or related disorders or have just started to notice symptoms.

Veterans have access to innovative strategies and treatment interventions to improve functional ability and life satisfaction as well as opportunities to participate in cutting edge research intended to lead to more effective treatments. Other PADRECC services may include but are not limited to multidisciplinary assessment and treatment, clinical trials, physician consultation, medical management, surgical interventions, neuropsychological services, physical and occupational therapy, speech therapy, nursing services, caregiver resources, educational materials, community education programs, patient and family programs, support groups and programs to educate medical professionals.

To learn more about the PADRECC program, please call the closest center for details or visit our website at www.va.gov/padrecc

Houston PADRECC	(713) 794-7841
Philadelphia PADRECC	(215) 823-5934 or toll-free (888) 959-2323
Portland/Seattle PADRECC	Portland: (503) 721-1091 Seattle: (206) 277-4560
Richmond/Southeast PADRECC	(804) 675-5931 or toll- free (800) 784-8381 ext 5931
San Francisco PADRECC	(415) 379-5530
West Los Angeles/	(310) 478-3711 ext 48001

Appendix E

Alternative/Holistic Therapies and Parkinson's Disease

Jill Marjama-Lyons, M.D.
Neurologist and Author
Los Angeles PADRECC

Frequently Asked Questions and Answers

What does "alternative medicine" really mean? "Alternative" is a term that implies a non-Western medicinal approach. It often refers to Eastern (Traditional Chinese, Japanese, Indian "Ayurvedic") methods of evaluating and treating physical conditions. Many therapies can fall within this category, but the more common ones include acupuncture, herbal therapies, homeopathy, manual therapies (massage, Reiki) spiritual healing, naturopathy, mind-body exercises (yoga, tai chi) and vitamin/enzyme supplements. The term "integrative," "holistic" or "complementary" are preferred instead of "alternative" because these imply an addition or combination of these therapies with established Western medicine approaches (dopaminergic drugs, brain surgery, rehabilitative therapies) into a comprehensive program for the individual person with Parkinson's disease.

What herbs are safe to take and are proven to help persons with Parkinson's disease? Herbs such as macuna pruriens, a plant that contains levodopa and can reduce some of the motor symptoms of Parkinson's disease are "over-the-counter" supplements such as vitamins, enzymes and amino acids and are loosely regulated by the Food and Drug Administration. This means that the quality, purity and content of any of these supplements are dependent upon the manufacturing company.

Almost none of these have been properly studied for the treatment of Parkinson's disease. As a consumer, you should contact the manufacturer directly with questions about the purity and safety of the product as well as consult a licensed specialist (i.e. herbalist, nutritionist) for advice before taking any supplement. Some herbs and supplements can interact with prescribed medications or cause unwanted side effects. A list of resources is available at the end of this handout to assist you.

Should people with Parkinson's disease take Co-Q10? Co-Q10 is not a proven treatment for Parkinson's disease at the present time. Co-Q10 is a vitamin-like substance found within the energy source of every living cell (the mitochondria). It has been shown to occur at lower levels in persons with Parkinson's disease (PD). A recent double-blinded study showed persons with PD who took Co-Q10 300 mg 4 times a day (1200mg total daily dose) scored 44% better on motor scales than the persons who took the placebo or "fake" pills over 16 months. This was a small study and whether Co-Q10 truly helps reduce motor symptoms or might delay the progression of PD is unknown. Future studies are needed to help us to better understand this. It was found to be harmless to the patients who took it in the study. However, it is expensive at about $200 a month for a 1200 mg daily dose. Many forms exist so if you decide to take it, look for Co-Q10 that is in liquid form and that the manufacturer guarantees its adequate absorption and purity.

Should persons with PD take NADH? Similar to Co-Q 10, NADH (nicotinamide adenine dinucleotide hydrogen) is an enzyme that is involved in energy production of living cells. NADH is not a proven treatment for Parkinson's disease. Several open-label (Patients and examiners were not blinded) studies have shown motor improvement in persons with PD who took NADH; One small double-blinded, controlled study of 10 persons with Parkinson's disease who took intravenous NADH did not indicate that any improvement occurred in patients.

Should a person take IV(intravenous) glutathione for Parkinson's?
Glutathione is not an approved treatment for Parkinson's disease. Similar to Co- Q10, glutathione levels have been shown to be lower in persons with PD. Despite many personal stories of patients feeling better with use of IV glutathione, currently there are no published controlled studies proving or disproving it as a therapy for PD.

What vitamins should people take if they have Parkinson's? There are no proven vitamins that specifically help reduce the motor symptoms of PD. One theory of the cause of Parkinson's proposes an excess of electrically charged particles called free radicals. Antioxidants, such as vitamin C and E help to reduce these free radicals and therefore, are vitamins to consider taking.

Can massage therapy help people with Parkinson's disease? Some persons with PD report massage therapy to lessen muscle stiffness (rigidity) and pain, though the benefit is often transitory and last a few hours or days.

Does exercise really make a difference? Exercise of any kind that does not increase one's risk of falling is always recommended to increase endurance, improve delivery of oxygen to the brain, heart and muscles, increase muscle strength and mass, and improve coordination, balance and flexibility. Exercises such as yoga and tai chi focus on the mind-body connection and improve balance and mobility for persons with Parkinson's. Many PD centers and health clubs offer formal yoga and tai chi classes.

What holistic therapies could be tried and where could a knowledgeable doctor be found? It is important to try therapies that fit your personality, schedule and budget and are readily available. You will need to spend some time and effort to educate yourself about a particular therapy before deciding whether to try it and then assess whether it is helping you. You will need to find a licensed specialist for the particular therapy you are considering. Some doctors who are more oriented toward holistic therapies include doctors of oriental medicine (D.O.M.), doctors of osteopathy (D.O.), naturopaths, homeopaths as well as licensed acupuncturists and herbalists. The list of resources on the next page is a good place to start.

About the Author:
Dr. Marjama-Lyons received her medical degree from S.U.N.Y Health Sciences Center in Syracuse, NY. She completed her internship at the University of Rochester and her neurology residency at the University of Arizona. She completed a fellowship in Parkinson's disease with Dr. William Koller at the University of Kansas. She currently works at the VA Hospital in Albuquerque, NM and at Northern Navajo Medical Center in Shiprock, NM and hopes to establish a Parkinson's Center in Albuquerque to provide patient services and perform research on conventional and alternative therapies for PD. She is co-author of *What Your Doctor May Not Tell You About Parkinson's Disease: A Holistic Program for Optimal Wellness* published by Warner Books. Dr. Marjama-Lyons is also part of the Los Angeles PADRECC network.

Resource List for Holistic Therapies

The American Holistic Health Association's Complete Guide to Alternative Medicine By William Collinge, M.P.H., Ph.D.

Alternative Medicine: The Definitive Guide Edited by Burton Goldberg (Future Medicine, 1998), features over 400 holistic practitioners

What Your Doctor May Not Tell You About Parkinson's Disease: A Holistic Program for Optimal Wellness By Jill Marjama-Lyons, MD and Mary Shomon (Warner Books, 2003)

PDR for Herbal Medicine (First Edition, 1999) Medical Economics Company

Prescription for Nutritional Healing By James Balch, MD and Phylis Balch (Avery Penguin Putnam, 2000)

Tyler's Herbs of Choice: The Therapeutic Use of Phytomedicinals By James E. Robbers and Varro E. Tyler

Eat Well, Stay Well With Parkinson's Disease By Kathrynn Holden, M.S., R.D. (Five Star Living, 1998)

The Brain Wellness Plan, By Jay Lombard, M.D. and Carl Germono

American Holistic Health Association P.O. Box 17400, Anaheim, California 92817 / (714-779-6152/ www.ahha.org

NIH National Center for Complementary and Alternative Medicine (NCCAM) 888-644-6226 / www.nccam.nih.gov

Mind Body Medical Institute 110 Francis St., Boston, Massachusetts 02215 / (617-632-9530) / www.mbmi.org

American Association of Oriental Medicine 433 Front St., Catasauqua, Pennsylvania 18032 / (888-555-7999) / www.aaom.org

Acupuncture Page Listing licensed acupuncturists in each state, www.acupuncture.com

The Homeopathy Home Page www.homeopathy.com

Nutritional Web Site www.nutrition.about.com

Appendix F

The National VA Parkinson's Disease Consortium: Intendifying the Realm of Specialty Care Across the Nation

Rebecca Martine, APRN, CS, BC, Chairperson
National VA Parkinson's Disease Consortium

Over the past 2 years, the VA healthcare System and Parkinson's Disease Research, Education and Clinical Centers (PADRECC) have devised an innovative model of healthcare delivery for chronic disease in the veteran population. This effort has now been reinforced with the recent development of the National VA Parkinson's Disease Consortium. The Consortium is designed to network nationally dispersed VA clinicians with expertise and/or interest in the fields of Parkinson's disease and related movement disorders. It serves as the foundation for collaboration and development in the areas of clinical expertise, scientific research and educational outreach. Consortium members are offered the opportunity to cooperate with PADRECC experts in strengthening the delivery of specialized care throughout the VA system.

The Consortium was commenced with a national conference in Miami, Florida from April 23-25, 2003 titled "Novel Concepts and Management Strategies in Parkinson's Disease." Approximately 75 VA clinicians selected from the allocated PADRECC service areas were invited to attend the conference as Consortium charter members. The six PADRECC directors presented a series of lectures focused on modern management and treatment modalities. Participants were also invited to share in the development of future Consortium endeavors during focus group meetings. In addition, the Consortium Advisory Committee was formed with a representative from each PADRECC facility and a representative from each PADRECC service area.

To date, the Consortium is comprised of approximately 150 multidisciplinary clinicians. Subcommittees were recently launched during the first Advisory Committee meeting in Philadelphia, PA on September 3, 2003. Incorporated subcommittees include communication, scientific research, patient education, annual conference and telemedicine services. These subcommittees will serve as channels for collective interests and the development of momentous contributions.

The Consortium is anticipated to mature into an influential society that will better serve the veteran population afflicted by Parkinson's disease and associated disorders. It will also continue to promote the recognition of VA clinicians as leaders in the area of research, education and most importantly, clinical care. The PADRECCs are excited about the many possibilities that lie on the horizon with the establishment and impact of the National VA Parkinson's Disease Consortium. Together, they will allow for revolutionary advancement across the spectrum of Parkinson's disease care.

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Appendix G

National VA Parkinson's Disease Consortium

Annual Goals and Objectives 2003-2004

The mission of the National VA Parkinson's Disease Consortium is to support the provision of optimal care and education for veteran patients diagnosed with Parkinson's disease and related movement disorders through advocacy, scientific inquiry and enhanced clinical expertise.

Educational Program Goals	***Objectives***
Serve as a mechanism for alliance and collaboration amongst VA clinicians with interest and/or expertise in the areas of Parkinson's disease and related movement disorders.	● Provide open membership for all clinicians within the VA healthcare system. ● Strengthen associations between the PADRECC network and nationally dispersed VA clinicians, including neurologists, geriatricians and other relevant disciplines. ● Present expert resources for treating VA clinicians with the support of PADRECC specialists. ● Collaborate with voluntary and federal organizations for the expansion of national Parkinson's disease awareness ● Maintain subcommittees that will implement specific elements of the Consortium mission. ● Enhance recognition and national impact of the Consortium mission through collaboration with the National Center for Outcomes Research.
Facilitate continued communication and exchange amongst VA clinicians in the fields of Parkinson's disease and related movement disorders.	● Supplement the national PADRECC newsletter with a Consortium focused issue or insert biannually. ● Create a link off of the national PADRECC webpage for Consortium matters and updates. ● Establish list serves for Consortium members on national and service-area levels. ● Establish conference call programs for Consortium members within each service area. ● Schedule regular conference calls for members of the Communication subcommittee.
Endorse patient advocacy through the	● Provide educational resources for Consortium

development of educational materials and programs for patients and family members.	members. ● Assist Consortium members in the development of educational materials and programs. ● Collaborate with established Parkinson's disease organizations such as the American Parkinson Disease Association and National Parkinson Foundation in the distribution of existing educational materials for patients and families. ● Collaborate with the PADRECC Associate Directors of Education in the development and execution of educational materials and programs for patients and families. ● Schedule regular conference calls for members of the Education subcommittee.
Provide educational programs and opportunities for advanced training in the fields of Parkinson's disease and related movement disorders to VA clinicians	● Collaborate with the PADRECC Associate Directors of Education in the development and execution of educational materials and programs for clinicians. ● Facilitate educational opportunities between PADRECC experts and Consortium members. ● Promote national training in Parkinson's disease care and treatment for multidisciplinary students, residents and fellows. ● Expand educational opportunities to ancillary disciplines such as occupational, physical and speech therapy. ● Provide educational resources for clinicians on the Consortium link of the national PADRECC webpage. ● Organize a national academic conference for Consortium members with relevant lectures and updates in the areas of clinical care and scientific research for Parkinson's disease and related movement disorders. ● Schedule regular conference call for members of the Education subcommittee.
Support the delivery of specialized care to veteran	● Assess the capacity for telemedicine at those sites

patients affected by Parkinson's disease and related movement disorders through the use of telemedicine services.	where members of the Consortium are located. ● Increase the capacity of the PADRECCs for the provision of consultation to non-PADRECC sites using telemedicine technology. ● Work with the Office of Care Coordination to create a movement disorders telemedicine toolkit to assist in the implementation of telemedicine services. ● Schedule regular conference calls for Consortium members interested in telemedicine and telehealth to help facilitate the use of this technology.
Promote advanced research by VA clinicians in the fields of Parkinson's disease and related movement disorders.	● Initiate a database of clinical and laboratory research interests/expertise among Consortium members. ● Provide periodic notifications of on-going research projects at both VA and non-VA facilities in the fields of Parkinson's disease and related disorders. ● Explore collaborative projects for Consortium members in the areas of clinical, basic science and health services research. ● Support ongoing PADRECC research efforts. ● Provide research updates for the Consortium segment of the national PADRECC newsletter. ● Schedule regular conference calls for members of the Research subcommittee.

Appendix H

National VA Parkinson's Disease Consortium Membership Application Form

Last Name: _____

First Name: _____

Middle Initial: _____

Credentials: _____

Name of VAMC: _____

Mailing Address: _____

City: _____ State: _____ Zip: _____

Phone(include area code): (_____) _____

E-mail Address: _____

Your Title: _____

Do you currently treat patients with Parkinson's disease or related movement disorders? If yes, how many? _____

If no, whom do you refer them to?

Do you have any specialized training in the treatment of Parkinson's disease and related movement disorders? If yes, explain.

Are you active in any national or local organizations focused on Parkinson's disease or related movement disorders? If yes, please list the organizations and/or groups.

Are you currently involved with any type of support or research programs for those with Parkinson's disease and related movement disorders? If yes, please explain.

Why are you interested in becoming a member of the National VA Parkinson's Disease Consortium?

Mail, or Fax the Application to:
Yuri Romaniuk, BSc.PH.
Consortium Coordinator/National PADRECC Administrator
VACT Healthcare System
950 Campbell Avenue
West Haven, CT 06516Fax: (203) 937-4755 Phone: (203) 932-5711 ext. 3334

Appendix I

Overview of Geriatric Education Centers

Geriatric Education Centers (GECs) train health professionals, health professions faculty, students and practitioners in the special health care needs of the older adult population. Since 1982, over 375,000 health professionals representing disciplines such as Public Health, Allied Health, Medicine, Nursing, Social Work, Dentistry, and Pharmacy have been trained. The GECs have an emphasis on Geriatric Interdisciplinary Team Training, Ethnogeriatrics, Distance Education programming and a focus on training those health professionals who practice in medically underserved areas. Currently, there are 46 GECs funded through the Division of Interdisciplinary, Community-Based Programs (DICom), Bureau of Health Professions (BHPr), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS). Projects supported by this funding must offer training involving four or more health professions, one of which must be allopathic or osteopathic medicine, and must address all of the following statutory purposes: (a) improve the training of health professionals in geriatrics, including geriatric residencies, traineeships, or fellowships; (b) develop and disseminate curricula relating to the treatment of the health problems of elderly individuals; (c) support training and retraining of faculty to provide instruction in geriatrics; (d) support continuing education of health professionals who provide geriatric care; and (e) provide students with clinical training in geriatrics in nursing homes, chronic and acute disease hospitals, ambulatory care centers, and senior centers.

The National Association of Geriatric Education Centers (NAGEC) is comprised of these 46 funded GECs. NAGEC's goal is to promote better health care for the nation's current and future population of older Americans through education of the public about aging-related issues. This is accomplished not only through the training of health professionals, but also through mentoring programs, programs that promote intergenerational interaction and expose youth from diverse backgrounds to various career opportunities in health careers.

For more information, please visit the NAGEC website at **www.hcoa.org/nagec**